ALERT

THE UNIVERSAL FELLOWSHIP OF METROPOLITAN COMMUNITY CHURCHES

News from the UFMCC on AIDS Legislation, Education, Research and Treatment.

May, 1988

HIV SCREENING FOR TRAVELERS NOT EFFECTIVE

Dr. James Chin, chief of epidemiology and forecasting for the World Health Organization's AIDS program, has stated that screening international travelers is not feasible or effective in curbing the spread of HIV infection.

On March 8, in a speech in London at the First International Conference on the Global Impact of AIDS, Dr. Chin said that screening program funds would be better spent on education and risk-reduction. He pointed out that there are many problems with screening travelers: how and where will the tests be done? Where will officials keep tourists while waiting for the results? How will they deal with the high false-positive rate associated with low-risk populations?

Chin further pointed out that anyone who is avoiding high-risk behavior is safe from the virus, no matter the prevalence of HIV in any given country.

Some countries have considered excluding HIV-positive travelers, in spite of WHO's regulations that only yellow fever vaccination certificates be required.

NATIONWIDE AIDS DEMONSTRATIONS April 29 - May 7

A network of AIDS advocacy organizations including ACT UP (AIDS Coalition To Unleash Power -- chapters in New York, Boston, Los Angeles, San Diego, Rochester, Philadelphia, New Jersey, New Orleans, and elsewhere) and similar organizations such as AIDS Action Pledge and the ARC/AIDS Vigil (San Francisco), MASS ACT OUT (Boston), OUT (Washington, DC), C-FAR (Chicago), and several chapters of the National Association of People with AIDS will conduct coordinated demonstrations and other actions in over 30 cities to focus public attention on the need for effective action on AIDS. Some of these actions will include nonviolent civil disobedience; others will be educational forums, fundraisers, etc. Persons who want to help out in AIDS advocacy could use this organizing effort to meet others in their area.

A coordinating group called ACT NOW (AIDS Coalition to Network, Organize, and Win), set up by these groups, organized communication for this effort, which is called Spring AIDS Actions '88.

For more info, including how to contact the group in your area, call the ACT NOW national coordinator Terry Beswick, (415) 647-7972, or write to ACT NOW, P.O. Box 146694, San Francisco, CA 94114-6694.

MORE HIV TESTING OF INMATES

The March 9, 1988 AIDS Policy and Law reports that California, Missouri, and Mississippi officials are calling for testing of inmates for HIV antibodies. California Gov. George Deukmejian (R) announced that random testing will begin in April in all state prisons. Three to five thousand inmates will be randomly selected for testing, to determine the extent of HIV infection in the prison system, and to help state officials plan for the future. Currently, all HIV+ inmates, as well as all inmates with AIDS and ARC are housed at the California Medical Facility in Vacaville, in a special AIDS ward. A second AIDS ward will soon be opened in the Chino California Institute for Men, because Vacaville is already full and the target of a suit by inmates, charging that the state's treatment of HIV+ inmates is "inhumane and atrocious".

Deukmejian also supports State Bill 1005, sponsored by Sen. John Doolittle (R), which calls for mandatory testing of all incoming state inmates.

St. Louis, MO, County Executive Gene McNary has ordered HIV testing to begin within a month for current inmates, and testing all new inmates within 24 hours, including those who are unconvicted, and merely awaiting trial.

The St. Louis Effort for AIDS, and the ACLU of Eastern Missouri have both opposed the plan, although the ACLU has not formally challenged the order, due to their concentration on AIDS legislation coming before the Missouri General Assembly.

In Jackson, Mississippi, "blind" testing of new inmates was begun in November, 1987. Ten out of 679 inmates have tested positive. Dr. Dave Newton, the Mississippi Dept. of Corrections medical director, has stated that this figure is not alarmingly high, and does not indicate a need for mandatory testing of prisoners, or segregated housing of those who are HIV+. The state's epidemiologist, Dr. Ed Thompson, does not agree, and feels that the proportion of HIV+ inmates is larger than in the general population, and has suggested that mandatory testing be instituted if segregated housing could be provided for HIV+ persons.

In a call for more education in Mississippi's prisons, Newton cited that the current education program has dramatically reduced reported rapes, homosexual activity, and tattooing.

BASILE CRITICIZES DEMOCRAT FOR "GLOVES INCIDENT"

(Washington, DC, April 4, 1988) -- Human Rights Campaign Fund executive director Vic Basile condemned Connecticut Attorney General Joseph Lieberman for wearing rubber gloves as a "protection" against AIDS. Lieberman, a Democrat, is running against Senator Lowell Weicker (R-CT) in Weicker's quest for a fourth term.

Lieberman wore the gloves during a visit to a homeless shelter to "pat down" the residents for cigarettes, drugs and weapons. In a letter to Lieberman, Basile said, "Your dehumanizing actions, in which you mislead the public into thinking that there is a risk of disease through casual contact, simply exacerbate the problems faced by people with AIDS and HIV infection. You have sent a message which contributes to the climate of ignorance and fear about AIDS and its related illnesses."

"Lieberman's behavior is reminiscent of when the Washington, DC police wore rubber gloves to arrest the AIDS demonstrators at the White House last June," said Basile. "We must speak out against this sort of behavior among elected officials, whether it is displayed by Republicans or by Democrats. Joseph Lieberman and others like him must learn that we will not tolerate treating people with AIDS as outcasts.

Basile contrasted Lieberman's actions with those of his opponent, Senator Lowell Weicker. "Weicker is exactly the opposite when it comes to displaying and acting upon his concern for AIDS and people with the disease," explained Basile. "He has on several occasions met with people with AIDS to discuss legislative strategy and policy matters with them. That's part of the reason he is such a strong voice on the issue."

Basile is concerned that Weicker is facing a serious re-election threat from Lieberman. "Because of his vocal support for lesbian and gay civil rights and responsible AIDS policy, Weicker may not receive support from traditional conservative Republican sources," he said. "The national lesbian and gay community must mobilize its resources to see that he returns to office. We can not afford to be without Lowell Weicker in the Senate."

The Human Rights Campaign Fund has already committed the maximum $10,000 permitted by federal law to Weicker's campaign. Campaign Fund supporters in Washington, Los Angeles and San Francisco have also organized fund raising events for him.

"This election has major implications for the future of our issues," Basile said. "Its significance extends well beyond the borders of Connecticut."

Basile urged gays and lesbians all over the country to make a contribution to Weicker's re-election campaign by making out a check to Weicker '88 and sending it to the Human Rights Campaign Fund at 1012 - 14th Street, N.W., Suite 607, Washington, D.C. 20005. Checks will be forwarded to the campaign immediately.

PNEUMOCYSTIS CARINII PNEUMONIA DIAGNOSIS

A rapid, sensitive, and non-invasive test for diagnosing the most common and deadly AIDS-associated infection, Pneumocystis carinii pneumonia (PCP), has been developed by scientists at the National Institutes of Health (NIH) in Bethesda, Maryland, and used successfully in patients treated at NIH and at San Francisco General Hospital. The technique uses a new, highly accurate method of identifying P. carinii organisms in the sputum of patients.

PCP, the leading cause of death in persons with AIDS, affects 70 percent of AIDS patients at some point in their illness. By 1991, 10 years into the AIDS epidemic in the United States, an estimated 100,000 Americans will have been diagnosed with AIDS-related PCP.

"The earlier we can detect PCP, the better the prognosis for effective treatment," Dr. Kovacs said in the March 10, 1988 issue of the New England Journal of Medicine. "Presenting symptoms of PCP often resemble less serious respiratory conditions, and it is important to establish the diagnosis and begin therapy promptly."

Currently, PCP is most frequently diagnosed by inserting a bronchoscope into the lungs and either irrigating the lungs to obtain fluid samples (lavage) or using the bronchoscope to obtain a tissue sample (biopsy). Although these techniques are generally safe and sensitive, many physicians are reluctant to use them because of potential complications, cost and discomfort to patients. Occasionally it is necessary to perform a biopsy through open lung surgery, a more risky and costly procedure.

As an alternative to these invasive diagnostic techniques, Dr. Kovacs and his colleagues induced patients to cough up sputum by having them inhale a saline mist generated by an ultrasonic nebulizer. This technique had previously been shown to be useful in diagnosing PCP by investigators at UCSF and at the University of Miami, but in only 55 percent of cases.

Of 63 patients at San Francisco General Hospital from whom sputum specimens were obtained, PCP was ultimately diagnosed in 49 patients, 46 by staining of sputum. Compared to two traditionally used stains, which identified 76 percent and 80 percent of the patients, respectively, the indirect immunofluorescence assay identified 92 percent of the patients with PCP. In a study of similar techniques at the NIH Clinical Center, 23 of 25 patients with PCP were diagnosed by staining of induced sputum.

"Staining of induced sputum is clearly a safe, non-invasive method for rapidly diagnosing PCP in patients with AIDS," Dr. Kovacs said, "and is a significant advance in our efforts to respond quickly with appropriate therapy for this major killer."

TRIMETREXATE WITH LEUCOVORIN: Decisions That Save Lives, Decisions That Kill

(By: John S. James)

On February 16 the U.S. Food and Drug Administration (FDA) and the National Institute of Allergy and Infectious Diseases (NIAID) approved the first-ever "treatment IND" for early release of an AIDS treatment -- trimetrexate with leucovorin for pneumocystis. The AIDS community rightly welcomed this step forward -- the first AIDS use of the FDA's widely publicized "new rules" intended to allow physicians to use promising drugs before full approval for commercial sale, in cases of serious or life-threatening illnesses. If it works as intended, the new approval should save many lives.

Unfortunately the trimetrexate ruling also contains a tragic flaw which will almost certainly result in many deaths of others who could be saved.

The New Approval: Who Can, Who Cannot Qualify

Under the new approval announced February 16, the NIAID will provide trimetrexate only for patients who have shown "a severe or life-threatening adverse reaction to the approved therapies" (quote from FDA/NIAID press release). The drug, available only from the NIAID, will NOT be provided for patients for whom standard therapies have merely proven ineffective -- but not caused severe or life-threatening toxicities. These patients will be left to die.

This ruling flies in the face of the recommendation of the eleven physicians who wrote the October 15 article in the New England Journal of Medicine. Their abstract concludes "that the combination of trimetrexate and leucovorin is safe and effective for the initial treatment of pneumocystis pneumonia in patients with AIDS and for the treatment of patients with intolerance or lack of response to standard therapies".

A spokesman for Warner Lambert, the manufacturer of trimetrexate, said that the restriction (against using the drug when all standard treatments had failed to work, though they had not caused a severe or life-threatening reaction) was an FDA decision; it had been explained to him once but he didn't recall the rationale. A spokesman for the FDA gave two reasons. First, the drug had not been approved; clinical tests had not been completed. Second, it is not a drug to be used lightly, as it was potentially lethal unless leucovorin was also administered. When we asked how these reasons applied when the only alternative was the death of the patient -- and the trimetrexate/leucovorin combination almost never had side effects severe enough to cause its use to be discontinued -- he had no meaningful answer but suggested we talk to the NIAID, which developed the protocol (with the help of the FDA, which approved it). He did say that individual cases might be considered under an emergency treatment IND -- an option we believe unlikely to happen in actual hospital practice, especially since physicians would

be applying for something explicitly not allowed in the new NIAID/FDA protocol. He also said that the question of whether to expand the conditions under which physicians could use the drug was now being considered by NIAID.

NIAID said, however, that the exclusion of patients for whom all standard treatments failed was an FDA decision. NIAID is now working on "protocol 30", which is designed for these patients; we have not seen protocol 30 since it has not yet been released, but it is part of a series of protocols designed for scientific use, not treatment access, so presumably it will have selection criteria which exclude many patients for whom trimetrexate treatment would be medically indicated.

We do not know why these patients were excluded from the treatment IND (which is designed for treatment access), since no one involved will take responsibility for this decision. The best guess is that the reason for it was to force a selected group of the patients affected into protocol 30.

The public had no input in this decision, hidden in the fine print of the first AIDS-related treatment IND, which was announced by surprise at the time of two major meetings where it was important for the FDA to look good. Persons with AIDS and as far as we know their physicians, also had no input. Unless compelling new information has developed since last October -- information unknown to the press offices of either the drug manufacturer or the FDA -- this access restriction could only be called a ghoulish decision to deny trimetrexate to pneumocystis patients for whom all other available treatments have failed -- despite the clear recommendation of the world's leading experts on the trimetrexate treatment, based on their published evidence. The press, which usually only rewrites official news releases on medical-treatment stories, largely missed what happened here.

NALTREXONE SAFETY NOTE: DOSAGE ERROR

A typographical error in the October 1987 AmFar Directory of Experimental Treatments for AIDS and ARC caused the recommended dose of naltrexone to be listed erroneously as "1.75 mb/kg". The intended dose was 1.75 mg per day. The erroneous dose was over 50 times too large and is potentially harmful. A photocopy of the section containing the error also went out (together with correct information) with material from Project Inform. Meanwhile Bernard Bihari M.D., the developer of the naltrexone AIDS/ARC treatment, has increased the recommended dose from 1.75 mg per day to 2.75 mg per day. For complete instructions including all the corrections, contact Project Inform, (800) 822-7422 from outside CA, or (800) 334-7422 within CA.

SUBSCRIBE TO AIDS TREATMENT NEWS

Send $25, per quarter ($8 for persons with AIDS/ARC) to: ATN Publications, PO Box 411256, San Francisco, CA 94141. Subscriptions include several back issues at no extra charge.

National Institute of Allergy and Infectious Diseases

Backgrounder

Trimetrexate

Questions and Answers

1. What is trimetrexate?

   Trimetrexate is an investigational drug synthesized and patented by Warner-Lambert Company. The drug has been studied extensively in cancer and now shows promise as a treatment for Pneumocystis carinii pneumonia (PCP), the leading cause of death in patients with AIDS.

2. How does trimetrexate work?

   Trimetrexate is an antifolate, which works by interfering with the body's utilization of the group of vitamins called folates. Folates are essential to metabolic processes in both Pneumocystis organisms and in human cells.

   When trimetrexate is taken up by Pneumocystis organisms it interferes with critical enzymes. In the laboratory, scientists have found that trimetrexate is approximately 1500 times more potent against Pneumocystis carinii than trimethoprim, which is currently licensed to treat PCP in combination with sulfamethoxazole.

3. How is trimetrexate given to AIDS patients?

   The treatment involves trimetrexate in combination with leucovorin, a form of the vitamin folinic acid. Leucovorin protects human cells from the lethal effects of trimetrexate. However, because leucovorin is not taken up by Pneumocystis organisms, the Pneumocystis organisms are not protected from the lethal effects of trimetrexate.

   Trimetrexate given in combination with leucovorin has been demonstrated to be well tolerated in more than 100 AIDS patients with PCP. In contrast, the two drugs now approved for treating PCP--trimethoprim-sulfamethoxazole and pentamidine isethionate--often cause side effects significant enough to result in discontinuation of treatment in 30-50 percent of patients.

4. What does the treatment regimen involve?

   In current clinical studies, trimetrexate is given by vein (intravenously) once a day for 21 days. Leucovorin is given 4 times a day for 24 days, either by vein or as tablets taken by mouth.

5. What is leucovorin and how does it work?

Leucovorin calcium is a form of the vitamin folinic acid. It was discovered, isolated and synthesized by Lederle Laboratories.

Prior to its use in combination with trimetrexate, leucovorin has been used as an antidote to counter the toxic effects of methotrexate, a commonly used cancer drug.

Leucovorin protects normal human cells from the toxic effects of drugs such as trimetrexate by supplying the appropriate form of folate whose synthesis is blocked by trimetrexate. Thus, human cells can be "rescued" from the lethal effects of antifolate drugs. Since leucovorin does not penetrate into Pneumocystis organisms, they cannot be "rescued" and are thus killed.

6. Does trimetrexate cure AIDS?

No, trimetrexate has no activity against the human immunodeficiency virus that causes AIDS. But the majority of deaths from AIDS are the result of "opportunistic infections," of which the most common by far is PCP.

7. What is PCP?

Pneumocystis carinii pneumonia (PCP) is the most common opportunistic infection associated with AIDS and is the leading cause of AIDS-related deaths. Pneumocystis carinii pneumonia is caused by a one-celled parasite and is characterized by fever, a dry cough, and shortness of breath. In its most advanced form, PCP prevents the transport of oxygen from inhaled air into the blood, lowering blood oxygen to dangerous or fatal levels.

8. How many AIDS patients have PCP?

At some point in the course of their disease, almost 70% of AIDS patients will develop PCP. According to the U.S. Centers for Disease Control (CDC), AIDS patients now account for 98% of all cases of PCP. Sixty-seven percent of all new AIDS cases are diagnosed because of the presence of PCP.

9. How can AIDS patients participate in clinical trials of trimetrexate?

Under the auspices of the National Institute of Allergy and Infectious Diseases (NIAID), large-scale studies are being conducted at federally funded AIDS Clinical Trials Units (ACTUs) throughout the country.

One comparative trial involves patients with moderate to severe PCP. Approximately half will be treated with trimetrexate-leucovorin (TMTX-LCV) and the other half will receive the standard therapy of trimethoprim-sulfamethoxazole (T-S).

In addition, separate trimetrexate studies are being conducted by

Warner-Lambert Company.

The NIAID and Warner-Lambert studies are considered Phase III clinical trials, usually the last research step before a manufacturer submits a new drug application (NDA) to FDA for the drug to be licensed for clinical use.

10. Which AIDS patients will receive trimetrexate in the clinical trials?

Because these studies are "double blinded," neither the patients nor the investigators will know who is taking which drug. Double-blinded studies reduce the possibility of bias in interpreting the results.

11. How can AIDS patients who have experienced adverse reactions to standard therapy obtain trimetrexate?

Patients with PCP who experience severe or life-threatening adverse reactions to conventional therapy (T-S and injectable pentamidine) may qualify to receive TMTX-LCV under a Treatment IND.

On February 16, 1988, the Food and Drug Administration (FDA) announced the approval of the application submitted by NIAID to give "Treatment IND" status to trimetrexate. This is the first drug for AIDS patients to receive a Treatment IND (investigational new drug) status under new FDA regulations that went into effect in June 1987.

Under this Treatment IND, NIAID will make trimetrexate available to physicians caring for patients who have experienced serious side effects to T-S and pentamidine. A physician may contact NIAID and receive TMTX-LCV by express mail delivery if the patient meets the criteria for participation in the FDA-approved Treatment IND protocol.

Alternatively, a patient who has experienced adverse reactions to therapy may be eligible to receive trimetrexate in an open study in the AIDS Clinical Trials Units.

12. What is the difference between the clinical trials and the treatment IND for trimetrexate?

The clinical trials are randomized, comparative studies in which one group of the patients will receive TMTX-LCV and the other will receive standard therapy for treating PCP. These studies are designed to offer definitive proof of the safety and effectiveness of TMTX for moderately severe and refractory PCP.

The Treatment IND is designed only for desperately ill patients with PCP who are intolerant to both standard therapies, and who thus have no therapeutic options available to them. All patients in the Treatment IND will receive TMTX-LCV.

13. How can someone participate in the Treatment IND or enroll in the clinical trials?

Physicians interested in participating in the Treatment IND Protocol

should call 1-800-426-7527 (in Michigan, 1-800-833-0014), from 8:00 AM to 8:00 PM (EST) Monday through Friday.

Physicians interested in enrolling patients in the randomized clinical trials may contact the NIAID AIDS Clinical Trials Unit (ACTU) in their region or call the above toll-free numbers.

14. Do patients pay for drugs in the comparative trials or under the Treatment IND?

No, the drugs will be provided free of charge to patients enrolled in the comparative trials and in the Treatment IND.

15. What previous studies have been conducted on trimetrexate as a treatment for PCP?

Prior to this research phase, trimetrexate was the focus of several preliminary studies. One study was reported in the October 15, 1987 issue of the New England Journal of Medicine. The study was conducted by researchers from the National Cancer Institute (NCI), NIAID, and George Washington University Medical Center in Washington, D.C. It involved 49 patients with PCP -- including 16 who had already failed to respond to standard treatment -- and reported a 70% response rate.

Another study involving 59 patients was conducted by these institutions and by the University of Southern California Medical Center in Los Angeles. This was a dose-seeking study designed to determine the safest and most effective dose of trimetrexate in treating PCP.

NIAID AIDS CLINICAL TRIAL UNITS (ACTU'S)

California

*Dr. John Mills
San Francisco General Hospital/ University of California at San Francisco
San Francisco, CA
415/821-8666
Contact Person: Marti Nash
415/821-5531

*Dr. Thomas C. Merigan, Jr.
Stanford University School of Medicine
Stanford, CA
415/725-3929
Contact Person: Virginia Tallman
415/723-6231

*Dr. David Golde
University of California at Los Angeles School of Medicine
Los Angeles, CA
213/825-1301
Contact Person: Dr. David Hardy
213/206-6414

*Dr. Alexandra M. Levine
Dr. John M. Leedom
Los Angeles County-University of Southern California Medical Center
Los Angeles, CA
213/226-7504
Contact Person: Yvonne Barranday/ Jane Sullivan
213/226-5225 or 226-5226

*Dr. Stephen A. Spector
University of California at San Diego Medical Center
San Diego, CA
619/543-6447
Contact Person: Candace McIvor
619/543-6447

*Originally called AIDS Treatment Evaluation Units.

#Originally called Clinical Study Groups.

District of Columbia

#Dr. Richard Schulof
The George Washington University Medical Center
Washington, DC
202/994-8395
Contact Person: Jane Courtless
202/994-3027 or 994-2417

Florida

*Dr. Margaret A. Fischl
University of Miami School of Medicine
Miami, FL
305/549-7416
Contact Person: Janie Reese
305/549-7323

Illinois

#Dr. John Phair
Northwestern University Medical School
Chicago, IL
312/908-8196
Contact Person: Lisa Williams
312/908-4114

Indiana

#Dr. Robert Jones
Indiana University School of Medicine
Indianapolis, IN
317/274-8115
Contact Person: Bess Zwickl
317/274-8456

Louisiana

*Dr. Newton E. Hyslop, Jr.
Tulane University Medical Center
New Orleans, LA
504/587-7316
Contact Person: Jennifer Istre
504/587-7316

Maryland

*Dr. John G. Bartlett
The Johns Hopkins Hospital
Baltimore, MD
301/955-3150
Contact Person: Carol Hendricksen/
Ed Fuchs
301/955-2898

Massachusetts

*Dr. Martin Hirsch
**Massachusetts General Hospital/
Harvard Medical School**
Boston, MA
617/726-3815
Contact Person: Ellen Godfrey
617/726-5596

#Dr. Kenneth McIntosh
Children's Hospital Corporation
Boston, MA
617/735-7621
Contact Person: Nancy Karthas/
Kerrie Flynn
617/735-6832

#Dr. Neil Blacklow
**University of Massachusetts
Medical School**
Worchester, MA
617/856-3158
Contact Person: Charla Andrews
617/856-3158

Minnesota

*Dr. Henry H. Balfour, Jr.
**University of Minnesota Health
Sciences Center**
Minneapolis, MN
612/626-5670
Contact Person: Su Reaney
612/625-1462

Missouri

#Dr. Lee Ratner
Washington University School of Medicine
St. Louis, MO
314/362-8836
Contact Person: Dr. William Powderly
314/454-0058

New Jersey

#Dr. David Gocke
Robert Wood Johnson Medical School
New Brunswick, NJ
201/937-7710
Contact Person: Doris Connolly
201/937-7710

#Dr. Edward Connor
New Jersey Medical School
Newark, NJ
201/268-8484 or 456-5066
Contact Person: Bessie Bryant
201/268-8452 or 268-8565

New York

*Dr. Raphael Dolin
University of Rochester Medical Center
Rochester, NY
716/275-5770
Contact Person: Peggy Christy
716/275-5871

*Dr. Ruy Soeiro
**Albert Einstein College of Medicine
of Yeshiva University**
Bronx, NY
212/430-2371
Contact Person: Lauri Vitagliano
212/430-3659 or 430-2371

#Dr. Roy Steigbigel
**State University of New York at Stony
Brook/Health Sciences Center**
Stony Brook, NY
516/444-1660
Contact Person: Ruth Ann Carpenter
516/444-1660

#Dr. Henry Murray
Cornell University Medical College
New York, NY
212/472-6800
Contact Person: Katherine Kelly
212/472-4769

*Dr. Donald Armstrong
Memorial Hospital/Memorial Sloan-Kettering Cancer Center
New York, NY
212/794-7809
Contact Person: Denise Bundow (KS)
212/794-7900
Other protocols: Chris Cusumano
212/794-8206

*Dr. Fred T. Valentine
Bellevue Hospital/New York University Medical Center
New York, NY
212/340-6401
Contact Person: Mary Ann Kiernan/ Howard Ngai
212/340-6565

*Dr. Henry S. Sacks
Mount Sinai School of Medicine
New York, NY
212/241-7856
Contact Person: Pamela Wiesen/ John Schalhoub
212/241-8902

#Dr. Michael Grieco
St. Luke's Roosevelt Hospital
New York, NY
212/554-7194
Contact Person: Dr. George McKinley
212/554-7192

North Carolina

*Dr. Dani P. Bolognesi
Duke University Medical Center
Durham, NC
919/684-3103
Contact Person: Dr. John A. Bartlett
919/684-5260

#Dr. Stanley Lemon
The University of North Carolina at Chapel Hill School of Medicine
Chapel Hill, NC
919/966-2536
Contact Person: none

Ohio

#Dr. Robert Fass
The Ohio State University Medical Center
Columbus, OH
614/293-8732
Contact Person: Jodi Malone
614/293-8732

#Dr. Michael Lederman
University Hospitals of Cleveland
Cleveland, OH
216/844-3245
Contact Person: Carol Johnson
216/844-8175

#Dr. Peter Frame
University of Cincinnati College of Medicine
Cincinnati, OH
513/872-4704
Contact Person: Peggy Hall
513/872-6977

Pennsylvania

*Dr. Monto Ho
University of Pittsburgh School of Medicine
Pittsburgh, PA
412/624-2692
Contact Person: Geraldine Tama
412/647-8123 or 647-8125

#Dr. M. Elaine Eyster
The Milton S. Hershey Medical Center
Hershey, PA
717/531-8399
Contact Person: Ann Hamory
717/531-8399

Texas

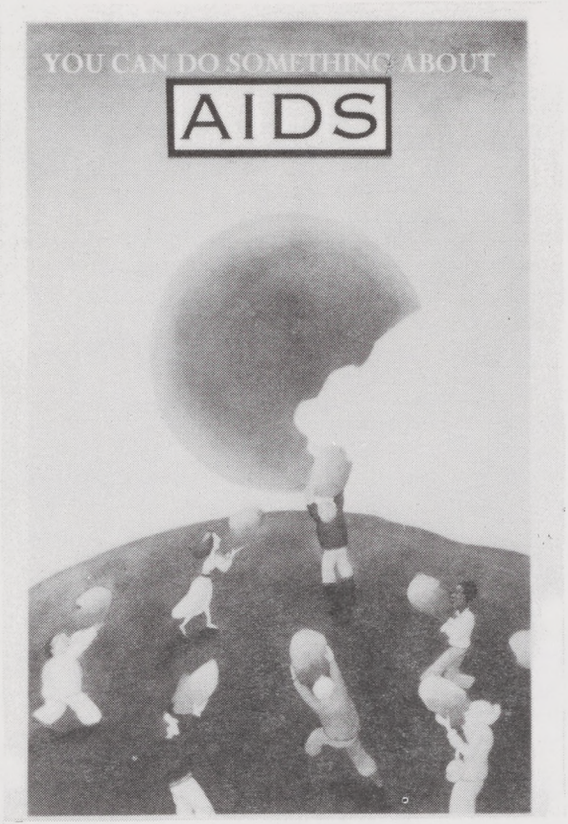
#Dr. Alan Barbour (outreach only)
University of Texas Health Science Center
San Antonio, TX
512/567-3938

Washington

*Dr. Lawrence Corey
University of Washington School of Medicine
Seattle, WA
206/526-2117
Contact Person: Dr. Ann Collier
206/223-4756

Prepared by
Office of Communications
National Institute of Allergy and Infectious Diseases
National Institutes of Health

February 1988



FREE AIDS ACTION BOOK

In an unprecedented cooperative effort, the publishing industry has joined together to make a free AIDS book available to consumers this June.

The book, titled YOU CAN DO SOMETHING ABOUT AIDS, contains forty-five short chapers, each outlining specific ways that individuals can help in the fight against AIDS.

Every chapter has been contributed by a different person; the writers range from local AIDS activists to nationally known figures. Among them are Elizabeth Taylor, Harvey Fierstein, John Preston, Whoopi Goldberg, Jody Powell, and Greg Louganis.

Sasha Alyson, head of Alyson Publications, has donated most of his time for the past nine months to coordinate the project. "The book industry has never before contributed money and services to provide a free book to the public," said Alyson. "To be honest, there were some at first who though the idea was crazy. But once it started catching on, the support became phenomenal."

The book will have a massive first printing of 325,000, and already, says Alyson, a second printing is being scheduled. It has received financial support from most major publishers including Harper & Row, the Bantam/Doubleday/Dell group, and Random House. Paper, printing, distribution, and publicity are all being donated. The Book-of-the-Month Club will offer the Book free to members this summer, and it will be given away in June by most bookstores.

PHYSICIANS AFFIRM DUTY TO CARE FOR PWA'S

The American College of Physicians has affirmed persons with AIDS' right to physician care, opposed widespread antibody testing, and suggested there be a national policy to share the accelarating costs of AIDS among a variety of private and public programs. The organization's March 3 Annual Meeting also opposed HIV testing by insurance companies, unless adequate financial resources are assured for every person with AIDS.

NEEDLE EXCHANGE PROGRAM IN BOSTON

Citing the success of needle exchange programs in Great Britian and the Netherlands, Boston Mayor Raymond L. Flynn (D) has called for a similar program to curb the spread of AIDS. Flynn states in his proposal, "Because our statistics have run about three years behind New York, we are still in a position to try to contain the spread." It is estimated that 25% of Boston's IV Drug Users are HIV+, while in New York, the positive rate among IVDU's is 70%. Religious and civic leaders, including Gov. Michael Dukakis, have already gone on the record against the proposal, claiming that it would encourage drug abuse. The program must be approved by the City Council, the state legislature and the governor.

CANADA INCREASES AIDS FUNDING

The Canadian Federal Government has allocated an additional $1.6 million towards AIDS research and education through the Federal Centre for AIDS, saving the Centre from a deficit in FY 1987-88, due to the increased activity of the agency. The money will fund educational videos, information pamphlets and research in Canadian laboratories. Also benefitting will be the Canadian Hemophilia Society and the Canadian AIDS Society, who are being funded for studies, conferences and counseling. Over the next five years, the Federal Centre for AIDS will receive funding totalling $40.6 million, including this most recent allocation.

NAN'S STRATEGY REPORT AVAILABLE

The National AIDS Network has published AIDS Into the 90s: Strategies for an Integrated Response to the AIDS Epidemic. The book reports on the community based response to AIDS, citing community agencies' central role in service provision their cost-effectiveness, and the diversity of agencies reflecting political, economic, cultural and demographic differences around the country. Strategies suggested in the report concern organizing and networking for the future, developing alternative sources of funding, and lobbying for more government money. Advocacy as education, the need for cultural sensitivity, the role of mental health workers, and providing assistance to care providers are also addressed. This short (42 pages) well-organized report is an important document for all concerned and is available from the NAN Clearinghouse & Resource Development Program, 1012 - 14th St. NW, Suite 601, Washington, DC 20005. Cost is $2 for Full Members of NAN, $5 for contributing members and $10 for non-members.

MOBILE AIDS BUDDY PROGRAM
A POSSIBILITY FOR THE SMALL CHURCH

MCC at Mobile was founded in 1985. It has 43 members, with an additional 15 people involved with the church. It is a very small church by almost any standards. However, with the AIDS crisis, MCC at Mobile is currently helping to care for 18 people with AIDS and providing emotional support for 6-8 more people who are HIV positive. We believe that what we are doing can be done by any group of people dedicated to being of service during this crisis.

Mobile is a Gulf Coast city, very old, traditional and conservative. Other than the church, the only visible gay community in the city are five bars and an organization which presents an annual Mardi Gras ball. The bar owners support the Mobile AIDS Fund, which distributes funds, as needed, to people with AIDS. There are 51 diagnosed cases of active AIDS in Mobile, along with about 200 more people who test HIV positive. MCC at Mobile takes care of about half the diagnosed cases with a full Buddy Program which can, as needed, provide food (cooked or as groceries), financial assistance, clothing, surgical supplies, wheelchairs, walkers, hospital beds and other equipment -- and a friend.

Many MCCs think they are too small, too isolated, too inexperienced to provide this kind of program -- but if it can be done at Mobile, it can be done anywhere.

MCC-Mobile AIDS Buddy Program

In spring of 1986, MCC, the Mobile AIDS Fund, and the Gay and Lesbian Community Council offered its first symposium on AIDS. At that symposium, a number of people showed interest in forming a Buddy Program to assist -- then -- University of South Alabama Medical Center with its care of AIDS patients. Invitations were extended to social workers, discharge nurses, counselors in the gay community, and other interested persons to become part of the Buddy Program either as buddies, as trainers, or as backup support for the buddies who felt overwhelmed or burnt out.

In October 1986, the formal training program of MCC-Mobile AIDS buddy program was begun, with a social worker from USA Medical Center and a psychiatric nurse as our first trainers speaking on confidentiality and the psychosocial needs of people with AIDS.

In January, 1987, a core member of MCC at Mobile became severly ill with AIDS dementia and had to be hospitalized. We were informed that we would have to provide 24 hour attendents for him or he would be shackled. For the first time, the Buddy Program geared up to meet needs in a crisis, and 24 people worked 8 days around the clock to care for this person. This brought us to the attention of a second hospital, and through their Assistant Director of Nurses, we were put in touch with a small group of community people who were trying to serve people with AIDS. We joined forces under the aegis of MCC, since we had the organization and the training already underway. Since the joining of those two groups and the leadership of that ADON, Jay Morton, the

program has increased in its ability to care well for patients, since the trainers available to us are of higher quality.

Also, through Mr. Morton, Springhill Hospital has become involved more with the Buddy Program, and in June 1987, donated the use of a building to MCC and the Buddy Program.

GROUP GIVES BIRTH TO MISSION OF CARING FOR HIV+ INFANTS

She is an accountant by training, running her own property management business. But, in her heart, Jeri Hendricks has known there is more important work for her to do. She has long been aware of how special children, especially babies, are to her. With her children grown and four grandchildren, she knew there were to be more babies in her life.

Last summer a probation officer called her, asking if she would be willing to be a foster parent to a 17 year old mother and her infant daughter, who was HIV+. She said yes, and three days later, she was licensed as a foster parent and was caring for the two of them. She knew through this experience, it was HIV+ babies to which she was to dedicate her life.

During an appointment with one of her accounting clients, Jeri found herself (much to her surprise) talking about her vision. She caught herself, and acknowledged to the client that she didn't know why she was sharing this information. The client responded, "I know why. I am supposed to be a part of this vision." Since that time, people who have heard about the project have come forward, knowing they, too, are supposed to be a part of creating a nurturing, healing environment for HIV+ infants.

A fast growing proportion of the new AIDS cases will be HIV+ infants who are born to infected mothers. In NYC, 1 of every 61 infants born is HIV+. Due to irrational fear and dread of the financial burden of caring for an infant who might not live very long, many babies are abandoned or turned over to social service agencies. Unlike our understanding of adults diagnosed with AIDS, infants who are HIV+ have a significant chance of throwing off the virus, once their immune systems begin to function. Given loving attention, touching, play and a chance to heal, many more infants can survive.

The House of Light seeks to provide such an environment for infants. Currently, negotiations are underway for a facility in a rural setting, that is ample enough to also consider eventually offering other AIDS-related services, ie, educational workshops, day treatment for diagnosed persons, and education and support for family members who cannot care for their infants.

The House of Light is a private, not-for-profit organization and is seeking funding from all interested individuals, groups, trusts and foundations. Tax-deductible donations may be sent to House of Light, P.O. Box 1532, Hillsboro, Oregon 97123.